Children with Special Health Care Needs
Family Satisfaction Survey

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Executive Summary

A survey was mailed to all Kansas families of clients participating in the Kansas Department of Health and Environment (KDHE) Children with Special Health Care Needs Program (CSHCN) on October 7, 2005. This was the second time CSHCN has utilized a survey for this purpose. The survey was designed to assess families' perceptions of how well the CSHCN program meets their needs. The survey focused on the following areas: application process; availability of information through the toll-free number the Make a Difference Information Network (MADIN); Health Care Plans; and service authorization process.

A total of 681 surveys were mailed to participating families in October of 2005. The two-page survey instrument included twenty-one (21) forced choice questions and an open-ended request for comments with each question. An overall response rate of 33.2% was achieved with 226 completed surveys returned. Of 226 completed surveys returned, 38 families responded via the Spanish language version.

Overall, the responses were positive for all of the questions that were related to the CSHCN program and staff including identifying the family's needs (93.7%), knowledge (95.4%), helpfulness (91.2%) and courtesy (97.7%). About 39.2% of respondents did not like the idea of an on-line or joint application for the CSHCN program.

Overall comments of the surveys showed that there is confusion about CSHCN services in relation to those provided by other entities such as the Kansas Department of Social and Rehabilitation Services and the Social Security Administration, Supplemental Security Income (SSI). Over 62% were unfamiliar with the MADIN toll-free number. The comments on Spanish language versions of the survey generally were very positive about the program services and interactions with the program staff.

A detailed analysis of the survey results has been used to develop a quality improvement plan for CSHCN. Priority areas for program improvement have been identified along with action plans and timelines for completion.

Background

In 1931, the Crippled and Chronically Ill Children's Program was established as Kansas Crippled Children's Commission. It was a health services program that offered diagnosis and treatment for children with severely handicapping conditions. In 1977, the Commission was transferred to the Kansas Department of Health and Environment (KDHE). In 1988, the law was changed replacing the term "crippled children" with "children with special health care needs (CSHCN)."

According to KSA 65-5a01, "a child with special health care needs" is defined as an individual under twenty-one (21) years of age, who has an organic disease, defect, or condition which may hinder the achievement of normal physical growth and development. The Maternal and Child Health Bureau, Health Resources and Services Administration, defines CSHCN as "children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

Services for Children with Special Health Care Needs (CSHCN) is a state and federally funded program. The program goals are to:

- provide early identification of children at risk for, or with, disabilities or chronic diseases;
- ensure availability of diagnostic and treatment services;
- assure that all children and youth with special health care needs have medical homes[1] responsive to their needs;
- promote the functional skills of young persons in Kansas who have a disability or chronic disease by providing or supporting a system of health care.

CSHCN assumes the following responsibilities: 1) Systems development activities – promotes the functional skills of young persons in Kansas who have a disability or chronic disease by providing or supporting a system of specialty care for children and families including specialized services and service coordination, quality assurance, and community field offices; 2) Make a Difference Information Network (MADIN) – Assists children and adults including those with disabilities, their families and service providers to access information and obtain appropriate resources. MADIN serves as the Maternal and Child Health (MCH) toll-free line.

The program is also responsible for the planning, development, and promotion of the parameters and quality of specialty health care for children and youth with disabilities in Kansas in accordance with state and federal funding and direction. More information on CSHCN is available at http://www.kdheks.gov/shs/indext.html.

[1] A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

Objectives

The second statewide family satisfaction survey was conducted with families of clients using CSHCN Services, KDHE as a measure of family satisfaction in October 2005. The first survey was conducted in 1999 and was designed to assess families' perception of how well the CSHCN program was fulfilling (meeting) the needs of families who were receiving CSHCN services and how the program might improve those services.

The second survey had similar purposes and asked similar questions regarding experiences with the CSHCN program and their staff as in the first survey. However, this survey was specifically developed to assess if the application process, MADIN, Health Care Plans and Service Authorizations were understood and helpful to families. At the time of the survey, the CSHCN program was looking at a new data system and wanted to ascertain what items were necessary to move to the new system. The program had written for a grant to help develop a web based joint application. The survey would give the program a chance to find out if families had an interest in this and which families have Internet access.

Methodology

The survey was a self-administered questionnaire developed at the CSHCN services, Bureau for Children, Youth and Families (BCYF), KDHE. Dr. Henri Menager, Epidemiologist, Cancer Control and Prevention, assisted in developing the survey. The survey was reviewed by CSHCN staff and also by CSHCN clinic staff. Charlie D. Hunt, Director of Epidemiologic Services, KDHE also assisted in reviewing the survey. The survey was distributed through the U.S. Postal Service (USPS). The survey questionnaire was available in both English and Spanish (Appendix 6).

The survey was distributed to 681 open cases that had a Health Care Plan as of September 21, 2005. Open cases are defined as those clients meeting eligibility criteria for the CSHCN program and those who are eligible for only case management due to receiving Supplemental Security Income (SSI) benefits.

The target dates for survey collection were October 10 - October 21, 2005. However, some were returned as late as January 2006.

Proprio (a translation service) was hired to translate the cover letter and the survey to Spanish. Robert Stiles with the Farm Worker Health Program at KDHE translated Spanish comments that were received from the completed surveys.

As completed surveys were received they were entered into a Microsoft Access database for analysis. All analyses were performed using SAS 9.1. Percentages shown in this report were calculated excluding missing values for the variable in question. Responses of "I don't know" or "Not sure" were also excluded from the denominator.

A survey follow up letter was sent out to the CSHCN families in February 2006 expressing appreciation and thanking those families who completed and returned the

survey (Appendix 7). The letter included brief survey results and brief explanations of services available through Services for Children with Special Health Care Needs (CSHCN), MADIN, SRS and SSI. Educational materials were included in the mailing.

With the help of A. J. Thomas with GeoSpatial Services at KDHE, Families of the 681 Clients served that had a Health Care Plan were mapped out. The map enhances visualization of the locations of the CSHCN families in Kansas (Appendix 1). These clients either met eligibility criteria for the CSHCN program or were eligible for only case management due to receiving SSI benefits as of September 21, 2005.

Results

A total of 681 surveys were distributed through the USPS with pre-paid return envelopes enclosed. Of those surveyed, 12 (1.8%) were returned because they could not be delivered. The main reasons were a wrong postal address or the family had moved and left no address and unable to forward. Of the surveys with correct addresses, as shown in table 1, 226 (33.2%) families completed the survey; 38 (16.8%) surveys were completed in Spanish. The total response rate was 33.2%.

Table 1. CSHCN Family Satisfaction Survey Response Rate

	All Clients		English Speaking		Spanish Speaking	
	Number	Percent	Number	Percent	Number	Percent
Total Survey completed and received	226	33.2	188	83.2	38	16.8

The clients served by the CSHCN program ranged in age from 6 months to 45 years with an average age of 11. A breakdown of age of clients by language spoken is shown in table 2.

Table 2. Age of Clients

	All Clients	English Speaking	Spanish Speaking
Age of Clients			
Average	11 yrs	11 yrs	10 yrs
Min	6 months	6 months	9 months
Max	45 yrs	45 yrs	20 yrs

(1) Experience with CSHCN program

Overall responses were positive for all of the questions that had to do with the CSHCN program and staff including helpfulness, knowledge, and courtesy as shown in table 3. Spanish speaking families' responses were very positive to the program and staff. The percentage of CSHCN families who rated their overall satisfaction as "very satisfied" or "somewhat satisfied" was 96.9% as shown in figure 1. Most families responded that the CSHCN program staff quickly identified their needs (93.7%), appeared knowledgeable and competent (95.4%), helped them understand how to use the CSHCN program (91.2%), and handled their needs with courtesy and professionalism (97.7%).

Figure 1. Overall Experience with CSHCN Program

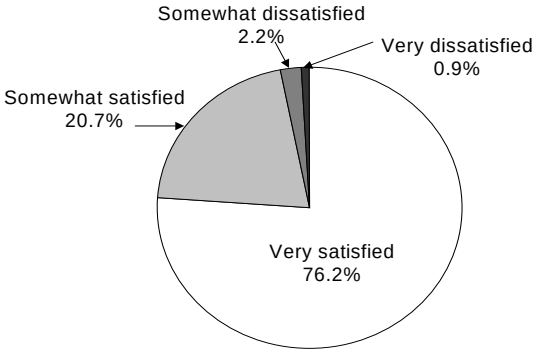

Table 3. Experience with CSHCN Program

	All Clients		English Speaking		Spanish Speaking	
	Number	Percent	Number	Percent	Number	Percent
Experience with CSHCN						
Overall						
Very satisfied	170	76.2	137	73.7	33	89.2
Somewhat satisfied	46	20.7	42	22.6	4	10.8
Somewhat dissatisfied	5	2.2	5	2.7		
Very dissatisfied	2	0.9	2	1.1		
Staff quickly identified the family's needs	207	93.7	170	92.4	37	100.0
Staff appeared knowledgeable and competent	208	95.4	170	94.4	38	100.0
Staff helped to understand how to use the CSHCN program	197	91.2	162	90.0	35	97.2
Staff handled the family's needs with courtesy and professionalism	213	97.7	175	97.2	38	100.0

All variables except total sample size (N) are listed as a % for the column attribute. Those subjects with missing values were not included in the calculation of the percentage.

(2) Application Process

As shown in figure 2, the majority of families (89.2%) responded that the overall application process was "very easy" or "somewhat easy". Overall, about half (48.2%) of the families had Internet access and only one-third (31.5%) of the families were interested in an on-line application. Of those with Internet access, 57.3% of families reported being interesting in an on-line application. Only 15.8% of Spanish speaking families have Internet access and only 8.8% were interested in an on-line application.

Although only half (48.7%) of the families were interested in a joint application with programs such as WIC (Special Supplemental Nutrition Program for Women, Infants, and Children), Infant-Toddler program, Medicaid and HealthWave, nearly three-quarters (71.1%) of Spanish speaking families showed an interest while a little over two-fifths (42.7%) of English speaking families showed an interest in a joint application. Overall, it seems that families with younger children were more in favor of a joint application. In comparing English and Spanish speaking families, English speaking families who have children younger than three were more interested in a joint application compared to Spanish speaking families who have children less than 5 years of age who are in favor of a joint application.

Figure 2. Overall Application Process

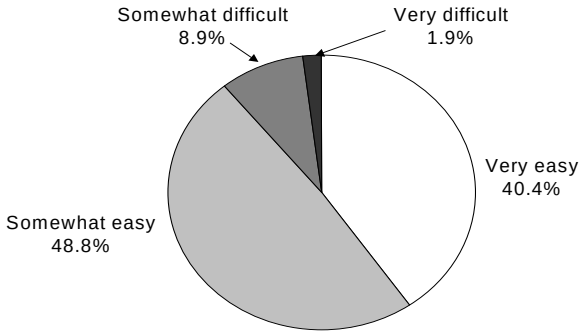

Table 4. Application Process

	All Clients		English Speaking		Spanish Speaking	
	Number	Percent	Number	Percent	Number	Percent
Application Process						
Overall						
Very easy	86	40.4	69	38.8	17	48.6
Somewhat easy	104	48.8	91	51.1	13	37.1
Somewhat difficult	19	8.9	15	8.4	4	11.4
Very difficult	4	1.9	3	1.7	1	2.9
Access to the internet	109	48.2	103	54.8	6	15.8
Interested in an on-line applications	68	31.5	65	35.7	3	8.8
Interested in a joint application						
All ages	97	48.7	70	42.7	27	71.1
Age <=3	16	59.3	14	58.3	2	66.7
Age <=5	29	59.2	22	53.7	7	87.5

All variables except total sample size (N) are listed as a % for the column attribute. Those subjects with missing values were not included in the calculation of the percentage.

(3) "Make a Difference" Information Network (MADIN)

The "Make a Difference" Information Network (MADIN) is an in-state toll-free number (Kansas and Kansas City Metro area only). It is available to assist children and adults including those with disabilities, their families and service providers to access information and obtain appropriate resources. MADIN serves as the Maternal and Child Health (MCH) toll-free line. The results of the familiarity and usage of the MADIN are shown in table 5.

Overall, nearly two-thirds (62.6%) of the families were not familiar with the MADIN; only one-fifth (21.2%) of the families reported having used it. Of those who are familiar with the MADIN, only 53.7% have used the line as shown in figure 3. More Spanish speaking families (47.2%) were familiar with the MADIN compared to English speaking families (35.5%). Fewer English speaking families (19.9%) used MADIN compared to Spanish speaking families (27.8%). It is apparent that many families are not familiar with the MADIN and have not used it.

Figure 3. "Make a Difference" Information Network (MADIN)

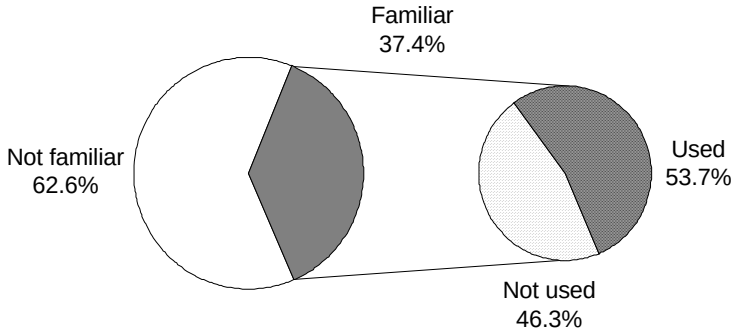

Table 5. Make a Difference Information Network (MADIN)

	All Clients		English Speaking		Spanish Speaking	
	Number	Percent	Number	Percent	Number	Percent
"Make a Difference" number						
Familiar with the "Make a Difference" number	82	37.4	65	35.5	17	47.2
Used the "Make a Difference" number	46	21.2	36	19.9	10	27.8

All variables except total sample size (N) are listed as a % for the column attribute. Those subjects with missing values were not included in the calculation of the percentage.

(5) Health Care Plan (HCP)

The Health Care Plan (HCP) is an individualized plan of care developed by the CSHCN program in cooperation with the family which identifies the client's medical home, specialty care, medical services, resources and funding sources (i.e., insurance, Medicaid, CSHCN). The results of the familiarity and the usefulness of the HCP are shown in table 6.

Although about three-quarters (71.4%) of the CSHCN families knew what the HCP was, the majority of families (95.2%) responded that the typed HCP that they received in the mail was "very helpful" or "somewhat helpful." Of those who knew what the HCP was, nearly all (97.3%) reported that the typed HCP was "very helpful" or "somewhat helpful" as shown in figure 4.

Only half (51.4%) of Spanish speaking families knew what the HCP was. Although the typed HCP is not provided in Spanish due to the fact that it is highly individualized, 96.7% reported that the HCP was "very helpful" or "somewhat helpful." All (100%) Spanish speaking families who knew what the HCP was reported that the typed HCP was "very helpful" or "somewhat helpful."

Figure 4. Health Care Plan

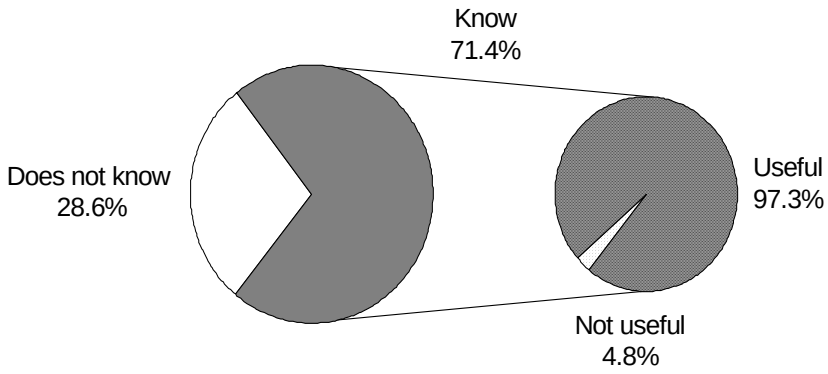

Table 6. Health Care Plan

	All Clients		English Speaking		Spanish Speaking	
	Number	Percent	Number	Percent	Number	Percent
Health Care Plan						
Know what the "Health Care Plan" is	155	71.4	136	75.6	19	51.4
Describe the typed "Health Care Plan" that received in mail						
Very helpful	111	59.4	84	53.5	27	90.0
Somewhat helpful	67	35.8	65	41.4	2	6.7
Not helpful	9	4.8	8	5.1	1	3.3

All variables except total sample size (N) are listed as a % for the column attribute. Those subjects with missing values were not included in the calculation of the percentage.

(6) Service Authorization (SA)

The Service Authorization (SA) is a statement of CSHCN funding commitment for eligible medical services. Coverage requires prior approval. If the client only received case management, there is no SA generated. The results of the familiarity of SA and the necessity of the HCP and/or SA are shown in table 6.

Only half (49.8%) of the CSHCN families knew what the SA was. However, most families (87.5%) indicated that both the HCP and the SA were necessary as shown in figure 5 and figure 6. These results held for both English and Spanish speaking CSHCN families as shown in table 7. A higher dissatisfaction rate was expected among Spanish clients since the HCP and SA is not provided in Spanish. Of those who indicated knowledge of the HCP and the SA, 60.1% indicated that both the HCP and the SA were necessary. Of those who indicated knowledge of the HCP or the SA, 86.7% indicated that both were necessary.

Figure 5. Service Authorization

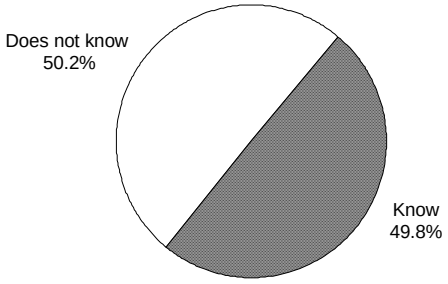

Figure 6. Need of Health Care Plan and/or Service Authorization

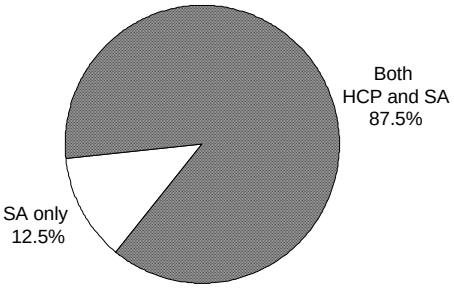

Table 7. Service Authorization

	All Clients		English Speaking		Spanish Speaking	
	Number	Percent	Number	Percent	Number	Percent
Service Authorization						
Know what the "Service Authorization" is	106	49.8	88	49.7	18	50.0
Both the "Health Care Plan" and "Service Authorization" are necessary						
Both	140	87.5	112	87.5	28	87.5
Only Service Authorization	20	12.5	16	12.5	4	12.5

All variables except total sample size (N) are listed as a % for the column attribute. Those subjects with missing values were not included in the calculation of the percentage.

(7) Method of Communication

Although most families indicated more than one preferred method of communication, overall about two-thirds (61.7%) of the families indicated U.S. mail as a preferred method of communication over telephone or email, especially in Spanish speaking families. The results are shown in figure 8 and table 8.

Figure 7. Method of Communication

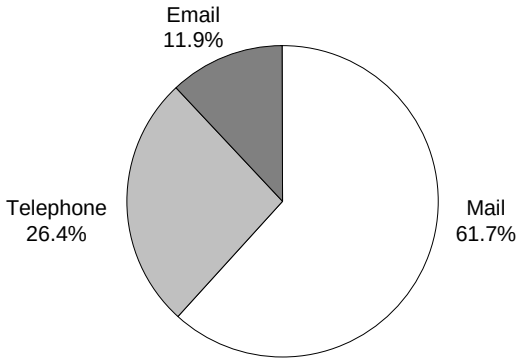

Table 8. Method of Communication (Response allowed more than one)

	All Clients	English Speaking	Spanish Speaking
	Percent	Percent	Percent
Communication method preferred			
Mail	61.7	59.5	73.5
Telephone	26.4	26.7	24.5
Email	11.9	13.7	2.0

All variables except total sample size (N) are listed as a % for the column attribute. Those subjects with missing values were not included in the calculation of the percentage.

Conclusions

1. Overall responses were positive for all questions that were related to the CSHCN program staff including helpfulness, knowledge and courtesy. Spanish comments were very positive. Many comments on the completed surveys related to Phenylketonuria (PKU) formula coverage, and appreciation for the coverage.

2. Families with younger children indicated interest in the joint application process. With increasing familiarity with and expanded use of the Internet with security features, it is anticipated the on-line/joint application feature will grow in popularity.

3. With a 33.2% rate of return surveys this indicates families do take an interest and respond when directly engaged. Future programs targeting and supporting family involvement should be considered when designing educational materials and when redesigning CSHCN forms.

4. Educational ad campaign in English and Spanish about the CSHCN program including MADIN may help in improving the program.

    a. It is apparent from results that many families are not familiar with the Make A Difference Information Network (MADIN) toll-free number (or know the 1-800 toll-free number, but may not be familiar with the name of the network) and have not used it. MADIN needs further explanation so families are aware of how to use the service. The MADIN toll-free number and website (which is under development) can serve as a vital connection to federal, state and local resources.
    b. Comments on the survey showed that there is confusion about how the CSHCN program relates to other programs like Kansas Department of Social and Rehabilitative Services (SRS) or Supplemental Security Income (SSI). There is a need of clarifying the CSHCN program and differentiate from SSI, SRS by using the term "CSHCN" instead of using the "Special Health Services (SHS)." SSI, SRS, SHS are too confusing for families and too similar. (The Bureau of Children, Youth and Families has changed their name to Bureau of Family Health in hoping that this will bring us in line with other bureaus that have "health" in their names and it will eliminate the confusion about our bureau providing social services.)
    c. Annual mailings to providers and health departments to help keep in touch – it is a way of getting out program information.

5. GIS mapping provides CSHCN staff a visual connection to distance traveled by families. Distance from specialty providers requires we do a better job coordinating appointments, including PCP as a member of the specialty team and scheduling appointments to complement weather and occupational needs.

Lessons Learned for Future Satisfaction Surveys

1. Questions related to the Health Care Plan and Service Authorizations need to be rephrased so that answers are more valid (e.g., if "yes" to these questions, please answer the following, etc.)

2. Methodology needs to be improved to increase the response rate by doing a follow up mailing. In order to assure confidentiality a reminder would need to go to all families to encourage participation. Initially, a second mailing was planned to follow-up in order to increase the response rate, but we felt the response rate over 30% did not warrant a follow-up mailing.

3. Diagnosis needs to be asked so that we would know the needs specifically as it seemed many responses were related to PKU.

Acknowledgements

We would like to acknowledge the CSHCN families who took time to complete the survey and return it. Without their willingness to share the information, this study would not be possible.

Special thanks to Dr. Henri Menager, Charlie D. Hunt, Robert Stiles, A. J. Thomas, and the CSHCN staff - Jane Kenney, Mary Ann Bechtold, Doris Hemme, Linn Goodell, Phyllis Copeland, Joe Johnson, Vicky McIntyre, Vicki Miller, Tawana Sanders, Julie McCoy, Jo Ann Matthews, and Marcia McComas for their assistance in this project. Without their support, collaborative efforts and excellent suggestions, this project would not have been accomplished.

Appendices

Appendix 1. A map of CSHCN families served
Appendix 2. Results of CSHCN family satisfaction survey
Appendix 3. Comments of CSHCN family satisfaction survey (English clients)
Appendix 4. Comments of CSHCN family satisfaction survey (Spanish clients)
Appendix 5. Cover letter of CSHCN family satisfaction survey (English and Spanish)
Appendix 6. CSHCN family satisfaction survey (English and Spanish)
Appendix 7. Follow up letter for CSHCN family satisfaction survey (English and Spanish)